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Chapter 5

Diabetes and the Pregnancy Paradox

The Loss of Expectations and Reproductive Futures

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In modern western societies, pregnancy, childbirth and early motherhood are often understood, and experienced, paradoxically. On the one hand, these experiences are epitomized as the most natural, joyous, special and even empowering of experiences. On the other, they can also be experienced as some of the most medicalized, technocratic, traumatising and disempowering of times. In this chapter we argue that diabetes in pregnancy sits at the very intersection of this paradox.

In 1989 the St Vincent's Declaration *Diabetes Mellitus in Europe* called for the outcome of pregnancies in women with pre-existing (Type 1) diabetes to be comparable with those of women without this condition; this declaration was made under the aegis of WHO Regional Office for Europe and the International Diabetes Federation. However, over 20 years on, diabetes remains the most common medical complication in pregnancy and is associated with increased risks to life and health for mother and baby including, obstetric complications, increased rates of caesarean delivery, increases in congenital abnormalities and perinatal mortality and morbidity (CEMACH 2007). Drawing on the relatively limited social sciences literature on this topic and on the findings of a consultation process involving women with pre-existing (Type 1 and Type 2) and gestational diabetes in pregnancy in the UK, this chapter sets out to explore how through this paradox, women with diabetes can experience a sense of reproductive loss throughout the pregnancy process.

Diabetes in Pregnancy: What are the Risks to Health?

Rates of diabetes during pregnancy are rapidly increasing in the UK, and elsewhere, and are seen to be a serious public health concern (CEMACH 2007). These increased rates are mainly due to the rapid rise in the numbers of women who have Type 2 diabetes and it has been suggested that this is associated with an increased prevalence of British people who are overweight and obese (Coulthard et al. 2008). Type 2 diabetes typically occurs later in life, and is usually treated with diet and increased physical activity initially but medication and/or insulin injections are often required to control the condition. Type 1 diabetes begins during childhood or early adulthood and requires the use of multiple daily insulin injections and testing of blood sugar levels in order to maintain health and wellbeing for the rest of one's life.

Outcomes for women with all types of diabetes during pregnancy tend to be measured in terms of infant morbidity such as congenital abnormalities, and infant and maternal mortality. A key report from the Confidential Enquiry into Maternal and Child Health, which focused on women with pre-existing Type 1 diabetes, highlighted a five-fold increase in still-births, a three-fold increased risk of perinatal mortality and a two-fold increased risk of congenital abnormalities (CEMACH 2010). The same report highlighted that preterm delivery rates were more than five times more common in women with Type 1 diabetes compared to women without this condition, and caesarean section rates were nearly trebled.

Research suggests that women who develop gestational diabetes (GDM) also have an increased risk of morbidity and mortality. GDM – diabetes which appears during pregnancy and usually disappears postnatally – occurs when the body cannot produce enough insulin to meet the extra needs of pregnancy. It is associated with

being overweight and also with a family history of Type 2 diabetes and is therefore also increasing in frequency as both of these conditions become more common. Although it usually goes away after childbirth, women with GDM have an increased risk of developing Type 2 diabetes later on in life as well as having GDM in subsequent pregnancies. Barahona and colleagues (2005) noted that gestational diabetes was a predictor for adverse maternal outcomes including hypertension, and adverse neonatal outcomes including prematurity, low Apgar scores, and perinatal mortality. However, adverse outcomes are more significant for women with pre-existing diabetes compared to women who develop diabetes in pregnancy. Both Type 2 diabetes and GDM are more common in women from minority ethnic groups and those living in deprivation (Casson 2006).

During pregnancy and childbirth, all types of diabetes introduce a range of challenges for women and those providing their care. Having diabetes means incorporating a whole range of self-care behaviours into daily life including blood testing, medication taking, and dietary restrictions. People with diabetes are also more likely to have mental health problems such as depression in comparison to people without this condition (Lloyd et al. 2010).

Current UK recommendations for the care of women with diabetes before and during pregnancy focus on medical considerations, especially achieving good blood glucose control. The main aim of this care is to reduce the risk of complications during pregnancy and childbirth. However, women have other non-clinical needs such as the need for peer and/or social support that are not always addressed, and which can affect the experience of pregnancy and childbirth.

Consulting with Women about their Experiences

Research in the UK has focused predominantly on the clinical care of women with diabetes in pregnancy, with little attention paid to women's psychosocial needs, experiences and expectations of care, in spite of the National Institute for Health and Clinical Excellence (NICE 2008) guidelines which recommend that women's needs and preferences for care should be taken into account. To address the relative lack of research in this area, a multidisciplinary team of academic researchers and health professionals worked together to prepare a proposal to be submitted to the UK National Institute of Health Research (NIHR) *Research for Patient Benefit* Programme.

Women with diabetes who had recently had a baby at a large NHS Trust in the West Midlands, UK, were invited to attend one of four discussion groups as part of a consultation process. The purpose of the discussion was to explore experiences of diabetes in pregnancy as a means of identifying significant potential research themes. Seventeen women of white Caucasian (n=13) or South Asian Mirpuri (n=4) origin participated in the discussions which were facilitated by either one or two academic members of the multi-professional group and attended by the specialist diabetes midwife, who was also a member of that group. The discussions, each of which lasted approximately 90 minutes, were digitally recorded and transcribed *verbatim*. The groups were held in an informal setting and the majority of women who attended brought their babies and/or younger children. Some of the data generated via this consultation process are presented here, together with data drawn from other social sciences literature in the field.

Reproductive Loss and the Loss of Futures and Expectations

As we have highlighted elsewhere, the study of human reproduction often focuses on reproductive success, and on the struggles to achieve this (Earle et al., 2008). The discourses that surround the subject of pregnancy and childbirth usually focus on positive outcomes and happy endings, without always acknowledging experiences of loss, many of which are incredibly common. Layne (2003) suggests that such discourses merely serve to exacerbate the experiences of those whose pregnancies do not end happily or; indeed; where pregnancies do not occur at all. As argued previously, reproductive loss refers to a wide range of experiences, including early and late miscarriages, stillbirth, perinatal, infant and maternal death, as well as infertility and assisted reproduction (Earle et al. 2008). To extend this even further, we argue here that diabetes in pregnancy, where pregnancies come to be defined as high risk, and mothers and children as at-risk, can also be included within the broad umbrella of reproductive loss. That is, in the widest sense, reproductive loss refers to the loss of expectations *vis-à-vis* idealized notions of ‘normal’, ‘natural’ and trouble-free pregnancies.

Previous research indicates that women who experience diabetes in pregnancy are often subject to additional surveillance. For example, a Swedish study of midwives revealed their beliefs that mothers-to-be with diabetes had a moral obligation towards their foetus to make healthy choices (Persson et al. 2010). This obligation manifested itself as an increased monitoring and control of the pregnancy by the midwife. The midwives in this study also admitted to monitoring and questioning any behaviour that deviated from, or was found to contradict, their prescribed advice. When ‘non-compliance’ with their advice occurred, this was regarded as irresponsible behaviour by the pregnant woman and often caused friction in the care relationship. Other research has considered the situation from the point of view of pregnant women. One such study

(Evans and O'Brien 2005) argues that women who have diabetes in pregnancy describe it as 'living a controlled pregnancy'. In other words, juggling diabetes and pregnancy was found to limit women's ability to be autonomous, limited their control of normal daily activities and subjected them to day-to-day control and supervision by both internal and external forces; that is, women could be subjected to self-surveillance and surveillance by health professionals and even others. Such women characterize their pregnancies as a series of personal struggles to balance their desire for autonomy with the challenges of being under constant surveillance and adapting to required lifestyle changes. Of course, managing diabetes can be a frustrating and challenging experience whatever the circumstances. Living with diabetes has been described elsewhere as an 'ever-present moral dilemma' whereby individuals try to integrate their condition and their prescribed regime within their desired lifestyles (Watts, O'Hara and Twigg 2010). This moral dilemma may well be compounded when combined with the moral expectations placed upon and internalized by pregnant women. Not only do such women need to factor in what it means to be a 'good' or 'successful' person with diabetes but, also, a 'good' mother-to-be with diabetes.

The following part of this chapter draws on the data from the discussion groups to examine women's experiences of pregnancy and diabetes, focusing on care during pregnancy, childbirth and the immediate post-natal period.

Women's Experiences of Diabetes and the Pregnancy Process

Care during Pregnancy

Our discussions highlight how care during pregnancy seems to be dominated by medical surveillance and a focus on *diabetes* care, rather than on pregnancy, to the

detriment of an anticipated ‘normal’, ante-natal experience. As one respondent succinctly summarises:

...as time went on I just accepted that ... it was more about the diabetes than the pregnancy.

However data show that there were high expectations of service provision although this was often reported as unfulfilled in practice. As highlighted by previous studies (Persson et al. 2010, Evans and O’Brien 2005) the over-riding focus on diabetes care – rather than the experience of being pregnant – led to some dissatisfaction even if the clinical (diabetes) care was perceived as good quality. Two participants commented:

...the diabetes side was fantastic, but may be just a bit more support with just being pregnant.

I think diabetes for me – well it did take a lot of the pleasure away, took a lot of the: ‘it’s my body’ – ‘it’s my pregnancy’ [away from me].

In some instances this dissatisfaction led to (and was probably influenced by) problematic relationships with health care professionals. This was particularly relevant when women felt themselves to be under close surveillance and some women reported feeling infantilized, for example:

Sometimes it’s the person that you’re seeing as well, if you don’t have a good rapport ... I’d just felt sometimes like I was a naughty schoolgirl, and I used to dread putting some of the [blood-glucose] readings in my diary.

... the doctor I encountered was awful – he was hideous – a most vile man and I walked out crying and I just thought, well how dare he tell me what I will and won’t do! ... You won’t eat this, you won’t eat that, you know what I mean? Particularly in the early stages of pregnancy when you’re throwing up and you have a dietician saying, ‘you can’t eat this’ and this is the only thing you can keep down.

... sometimes I was spoken to like I was a piece of crap on the floor ... and I felt like.. well you are telling me things here that I know and that are not the situation.

Lawson and Rajaram (1994) noted that women with diabetes in pregnancy struggled with the various possible definitions of their pregnancy as 'normal', 'abnormal' or 'illness'. Persson, Winkvist and Mogren (2010) describe women with gestational diabetes as being 'stunned', and highlight the loss of a sense of normality, both in terms of the loss of a 'normal' pregnancy, as well as the loss of normal lifestyle. Most apparent in our discussion groups was recognition that the management of diabetes spoiled the notion of a happy, normal pregnancy free of problems and complications, as the following two women indicate:

It [the diabetes] just dominates the pregnancy all the way through, takes all the joy out of it.

Immediately you become high risk – it's in your notes. You'll probably be... induced early and it just changes everything so quickly.

All the women we spoke to, regardless of their type of diabetes, reported feeling that the health care professionals' over-riding concern was with their diabetes, in particular blood glucose levels and insulin treatment, at the expense of a more positive experience of pregnancy and childbirth. A Swedish study of diabetes in pregnancy noted similarly that: 'The healthy parts of the pregnancy had been forced into the background and there was too much focus on diabetes.... [this] easily can be overlooked and especially when a disease is present' (Anderberg, Berntorp and Crang-Svalenius 2009: 166-8).

Some of the women in the discussion groups had attended diabetes ante-natal clinics that were jointly run between the diabetologist and the obstetrician, and these were perceived positively because of improved communication between health care professionals.

Many of the women reported only seeing health care professionals in hospitals and did not have access to a community midwife during pregnancy. Not only did this

reinforce the medicalized nature of their pregnancy, it also engendered feelings of isolation as they spent their time in large busy hospital clinics, rather than at smaller, local settings in the community where women with low risk pregnancies are seen. This segregation added to feelings of being 'different' from other pregnant women who were experiencing a 'normal' pregnancy; a finding also noted by Thomas (2003) in her study of pregnancy and chronic illness.

To summarise, whilst experiences of diabetes in pregnancy are not all the same, the women who participated in our discussion groups highlighted a tension between the medical management of diabetes and the experience of pregnancy, the former of these being prioritized by health professionals in the delivery of care. Women seem to need a greater emphasis on the experience of being pregnant, seeking to emphasise the 'normal' and 'natural' aspects of the experience rather than those associated with the increased surveillance and monitoring of a medical condition. It is this very juxtaposition of anticipated normalcy against the medicalization of the pregnancy which presents a loss of expectations for women during pregnancy.

Care during Labour and Delivery

In contrast to experiences of care in pregnancy, where the women felt that there was too much emphasis on managing diabetes at the expense of other dimensions of their pregnancies, in labour, some of the women felt that further support from specialist diabetes care staff would have been helpful. For example, two participants commented on this:

My insulin drip came out and no one seemed sure whether they should put I back in or not.
When you're in labour ...it would have been nice to have a diabetes nurse or doctor to reassure you that everything's alright... although I had the drip in I don't remember anyone talking to me about my diabetes.

Similar findings were noted by Anderberg, Berntorp and Crang-Svalenius who argue that: ‘This focus on diabetes was relevant for all areas of care except for delivery department, where the situation was reversed. The women felt that focus there was predominantly on the normal and experienced that responsibility for the control’s necessary for their diabetes rested heavily on them.’ (2009: 166). Whilst the joint diabetes/obstetric service during pregnancy was seen as a positive aspect of service development, the same could not be said in relation to women’s experiences of labour. Indeed, one of the women in our discussion groups felt that she needed to remind staff that she had diabetes:

Although they were aware of it I had to keep reminding them. ‘Oh is it OK to have these?’ I had nothing to eat.

In their study of experiences of support during pregnancy and childbirth of women with Type 1 diabetes, Berg and Sparud-Lundin (2009) also found that women felt abandoned during childbirth when it came to managing glycaemic control. Indeed, little information had been given to the women to prepare them for the possible consequences of diabetes for childbirth, as one woman commented:

I don’t think I even thought that it would make any difference to my labour. Not at all, I don’t remember them saying they would test me during the labour or anything. Because I hadn’t been through it before, I didn’t know what to expect. But I know for next time, I’m guaranteed to get diabetes again so I’m booking in for a c-section!

Here, a gap between information received from diabetologists and information from midwives and obstetricians – as well as a lack of communication within the health care team – was in evidence, highlighting the differences between different teams and professions, as well as between generalists and specialists. A lack of joined up care has also been identified by another team of researchers in Sweden (Berg and Sparud-Lundin

2009) who suggest that women are often the ones that communicate between health professionals because information is not effectively shared between members of health care teams.

Childbirth is often described as a joyful, even empowering experience, albeit a painful one. However, even the pain of childbirth has been described in positive terms in anticipation of a happy event: a live and healthy baby. The data presented here, and other literature, suggest that childbirth experiences can be marred by the way in which women are expected to take responsibility for managing their diabetes during labour and delivery even if they are not really equipped to do so. During pregnancy, diabetes is at the fore of medical care but during childbirth the reverse is true.

Care after Childbirth

Data from the discussion groups suggest that in the immediate post-natal period, women are expected to take responsibility for their diabetes even when they do not necessarily have the knowledge or experience to do so. In contrast to the pride of place diabetes has during pregnancy, after birth (as during labour), diabetes is neglected, as one participant comments here:

On the post-natal ward when my blood sugar was so high, nobody there knew why it was and what to do about it...you've got a new baby who needs attention but your blood sugars are through the roof...

As reported by Sparud-Lundin and Berg (2011) in their Swedish study, health professionals may reinforce women's feelings of vulnerability during early motherhood since they (like women themselves) may have insufficient knowledge about managing diabetes, or may appear unconcerned or ignorant.

A number of the women in our discussion groups also reported some distress after being separated from their baby immediately after the birth, or very shortly after, when

they were sent to neonatal care for further monitoring. Sparud-Lundin and Berg (2011) suggest that women's vulnerability following childbirth can be reinforced in the early post-partum period when women and babies are separated. Two of the participants talked about being separated from their baby:

... we did have her for about an hour....that was hard there were three women with their babies crying all night (in the ward room she shared) then there's me. I felt like I didn't have a baby.

Then someone took him under the arms and he left. I thought where has he gone?

... they got someone from special care they said the baby didn't register on the scale so we have to take him away so we had a quick cuddle and he was gone. He was gone.... So that was a weird experience.

Another participant compares her recent experience of being able to stay with her baby to a former experience where her baby was taken into neonatal care:

Yes when I had my first about two hours after he was born they tested his sugars and it had dropped so they whisked him off to the special care unit where he was for two to three days. But they do it differently now – just come and test her – I think it is every couple of hours and she can stay with me and that is so much [better]. When you think you have gone through the pregnancy, people testing your blood all the time, it was lovely being able to keep the baby with me rather than being taken away and that is a new thing as I say and that was much better.

The CEMACH report, *Diabetes in Pregnancy: Caring for baby after birth* (2007) revealed that in more than 50 per cent of women with Type 1 and Type 2 diabetes, babies are automatically moved to neonatal care when there is no specific medical indication for admission. The report goes on to suggest that hospitals should be encouraging early interaction between mothers and babies unless there are contraindications and not simply separating women from infants because it is 'hospital policy'. Thus, women with diabetes are far more likely to experience the immediate

removal of their infant into neonatal care than are women without diabetes, and the subsequent losses that arise from this in relation to early interaction.

The same report (CEMACH, 2007) also highlights the impact of diabetes on breastfeeding, noting that a quarter of babies were not fed early enough and that two thirds of babies were given infant formula as a first feed. The report is conclusive in arguing that there is no reason for women with diabetes not to breastfeed, should this be their choice. Some of the women in our discussion groups felt undermined when trying to breastfeed in hospital:

... I explained that I was stressed and they made me sit there and breast feed her in front of them to make sure I was doing it right. Now when I think back I don't know why I didn't say, 'Oh just get stuffed', but your hormones are everywhere.

They came in didn't say anything just took his blood sugars, they just came with this bottle said 'is this OK?'. I said no because I'm breastfeeding her, they said they had to because her blood sugars were low, I was quite upset about this... I wanted to breastfeed her but because his blood sugars were low they were giving him formula and they said that I had to give him formula to get his blood sugars up. And then it took four, five weeks to get him feeding off me and it was just such a trauma...

Other studies have highlighted how the initiation of breastfeeding is an important part of the transition to motherhood. However, the data from this and other studies suggest that little support is available in the immediate post-natal period to support breastfeeding particularly in the context of managing blood-glucose levels (Rasmussen et al. 2007, Sparud-Lundin and Berg 2011). So, whilst not all women will choose to breastfeed, and women without diabetes may also struggle to receive the support they need to initiate and maintain breastfeeding, women with diabetes have an additional burden since they must negotiate this within the context of their experience of diabetes.

Diabetes can also have a significant impact on women's future plans regarding pre-conception care, pregnancy management, expectations around labour, delivery and the post-natal period. Planning for future fertility and family size was also an issue. In the quote below one of the participants with pre-existing diabetes describes her feelings:

I got pregnant after having 12 miscarriages. I think the preconception frightened me a little bit, and we did question, are we going to bother doing this? 'Cause I think it was the horror stories, the risk of stillborns and all this, you just start thinking, 'can I really put myself through all this'?

In the next two quotes, women with GDM talk about their anxieties in relation to possible future pregnancies:

I know if I had known... well what seriously put me off having another baby would be the insulin. The first time wasn't too bad – I was about 30 weeks pregnant so that wasn't too bad and it was OK with the diet – but this time they seemed to jump in so quick with the insulin and I kept says' no, no I'm not going on insulin until I have really got to ...

It didn't affect me with Hannah as it [GDM] was only picked up in the last 8 weeks, but with this one it was from week 8 – it kind of takes over your whole life so yes I'd think carefully about a third one.

In the final quote below, one participant describes the impact of diabetes on other people and in this instance, on her husband:

...with the second one, I was more concerned because I knew what had happened during the first. And my husband saying, never again, I never want us to go through that again, but we did and he was petrified. I know, at the beginning of the pregnancy, he used to phone five or six times a day because, I mean, he used to come home and find me unconscious with the second time pregnancy, I thought he was going to leave me he was so absolutely petrified at what he was going to come home and find.

So, in the immediate post-natal period the data from the discussion groups presented here suggest that – as experienced during childbirth – women themselves are

often expected to take responsibility for managing their diabetes, diverting attention from the transition to motherhood, recovery from labour and delivery and early interaction with their baby. Women with diabetes are also more likely to have their baby taken into neonatal care, and may experience more difficulties – for a variety of reasons – in establishing breastfeeding. All of these events can be experienced as a form of loss. In addition to this, diabetes can influence women's decisions regarding their future fertility, and can have an effect on other family members.

Final Thoughts on the Pregnancy Paradox

There is a fairly limited social sciences literature on diabetes in pregnancy, although its application can shed light on the impact of this condition on experiences of pregnancy, birth and early motherhood (Stenhouse and Letherby 2011). Our data, and other literature, suggest that a chronic illness such as diabetes can impact significantly on women's experiences of pregnancy, leaving some women feeling infantilized, under surveillance and overly medicalized. It would seem that women are deprived of the many simple pleasures of pregnancy because as one of the participants clearly states, the experience is '*more about the diabetes than the pregnancy.*' Whilst not all experiences are negative by any means, and there are many examples of good care, there is an overall loss of the sense of normality. In being diagnosed with diabetes or defined as high risk there is also the loss of a normal lifestyle, with restrictions on diet, requirements to monitor blood-glucose levels and the need to attend regular medical appointments in what might be a large, unfamiliar setting. In labour and in the immediate post-natal period, an expectation that women will manage their diabetes, even though they may not be equipped to do so, also contributes to the loss of a sense of normality. For some women, this experience is compounded further when their baby is

removed to neonatal care or they experience difficulties in establishing breastfeeding because of their diabetes. The impact of diabetes on future reproductive decision-making is also important as negative experiences, the fear of administering insulin or the fear of infant mortality or morbidity can have consequences for women and their families. For some women this implies a loss of the idealised notion of trouble-free pregnancy, whereas other women may feel the need to curtail desired future pregnancies.

Women with diabetes in pregnancy are not a homogenous group. Some women will have had diabetes from a very young age, whereas others will develop diabetes in their early adult years before pregnancy. This form of diabetes is often associated with being obese or overweight, but it is also more common in women who are from minority ethnic groups, as well as those who live in deprivation. Other women will develop diabetes for the first time during pregnancy and this is sometimes detected early on in a pregnancy but, for other women, it sometimes develops, or is detected just shortly before delivery. These differences influence women's experiences and the extent to which diabetes in pregnancy is experienced as a form of reproductive loss. Regardless of this heterogeneity, pregnancy, childbirth and early motherhood are experienced paradoxically against a backdrop of anticipated normalcy, where all women will be, and want to be mothers, where all pregnancies are wanted and successful, and where experiences of the pregnancy process are expected to be happy and fulfilling (Earle and Letherby 2003).

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